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Measuring quality of life and dignity in palliative care research

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Summary

Palliative care is the active, total care for patients and their families who face the problems associated with a disease that is not responsive to curative treatment. The palliative care approach focuses on controlling all aspects of suffering – physical, social, psychosocial and spiritual. The intention is neither to prolong life nor to hasten death but to enhance the quality of life of patients and their families. The ageing population with increasingly more people suffering from chronic diseases means a growing number of people will be in need for palliative care. Palliative care research is of utmost importance in informing policymakers and improving clinical practice. However, many practical and ethical challenges are associated with research in this field, particularly because patients in the last phase of life are rarely stable, are often cognitively impaired and the type of intervention they receive varies. There is a lack of conceptual clarity and wide range of definitions in research on palliative care. Determining appropriate outcomes and identifying measurement instruments for the adequate assessment of outcomes is challenging. Quality of life is the main focus of palliative care and therefore considered as an important outcome measure. Dignity is increasingly considered as a goal of palliative care but is a relatively new concept in this field.

This thesis contains three parts of which the first focuses on research methodology in palliative care research in long-term care facilities. Part II focuses on measuring quality of life in palliative care and part III on personal dignity at the end of life. We hope to contribute to a better understanding of the current state of the art in palliative care research in long-term care facilities as these facilities are becoming more important in the provision of palliative care for older people, and to provide helpful information about measuring the concepts of quality of life and dignity in research in palliative care.

Part I – Research methodology in palliative care research in long-term care facilities

In Chapter 2 the methodological rigour in palliative care research in long-term care facilities in Europe is explored. In order to find all papers reporting on patient outcome data of palliative care populations residing in long-term care facilities in Europe we performed a systematic literature review. Fourteen mainly descriptive studies were found. None described their study population specifically as a palliative care or end-of-life care population, most were conducted in the Netherlands and many different measurement instruments were used, mostly as proxy ratings to measure symptoms and symptom management. To improve future research on palliative care in long-term care facilities, agreement on what can be considered as palliative care in long-term care facilities and the availability of well-developed and tested measurement instruments is needed to provide more evidence, and to make future research more comparable.

Part II - Quality of life as outcome measure in palliative care

Chapter 3 provides an overview of the content and domains measured by the quality-of-life instruments that are appropriate for use in palliative care. First, we performed a non-systematic literature review to identify the domains most important for the quality of life for palliative care patients. A quality-of-life framework was developed including the following domains: physical comfort, physical functioning, cognitive functioning, psychological,

social and spiritual wellbeing and perceived quality of life. A second systematic literature review identified 29 instruments suitable for use in palliative care and in measuring quality of life. None of these instruments covered all aforementioned domains but only one or two quality-of-life domains. As spirituality is not well defined but considered as an important issue in palliative care we specifically focused on the domain of spirituality to find out how this domain was operationalized in the instruments. Most of the spiritual items concerned the meaning or purpose of life.

Chapter 4 is also based on the systematic literature review that identified the 29 quality-of-life instruments but this chapter reports the instrument characteristics such as target population, number of items, time needed to complete them etc. In order to assess the clinimetric quality of the instruments we evaluated the measurement properties by use of a widely accepted rating list. None of the instruments demonstrated satisfactory results. As not all measurement properties of all instruments have yet been adequately tested, we have not been able to provide an explicit recommendation for the use of one specific instrument. Overall, the MQOL, followed by the QUAL-E and the QODD, received the best ratings for their measurement properties. The information about practical aspects and clinimetric quality of the instruments can help clinicians and researchers in their choice of an instrument. The evaluation of existing instruments with good content validity should have priority over the development of new instruments.

Part III - Dignity as outcome measure in palliative care

Chapter 5 describes how we analysed the construct of personal dignity in addition to the evaluation of the content validity of the Patient Dignity Inventory. Data for this study were collected within the framework of an advance directives cohort study. One half of the cohort (n=2537) received a questionnaire including the Patient Dignity Inventory whilst the other half of the cohort (n=2404) received a questionnaire including an open-ended question on personal dignity. Content labels were assigned to issues mentioned in the responses to the open-ended question. The COSMIN checklist ('CONsensus-based Standards for the selection of health status Measurement INstruments') was used to assess the relevance and comprehensiveness of the items of the Patient Dignity Inventory. The study demonstrated that the items of the Patient Dignity Inventory were relevant for people with an advance directive, and that in addition to being valid for use in terminally ill cancer patients, the Patient Dignity Inventory can be used in a general population to obtain insight into people's thoughts about what would constitute dignity in the last phase of their life, although the comprehensiveness of the Patient Dignity Inventory can be improved by including items concerning communication and care-related aspects, and specifically phrasing of the items can improve the Patient Dignity Inventory.

Chapter 6 examines whether health status affects the perceptions of factors influencing personal dignity at the end of life, and the relationship between those perceptions and socio-demographic characteristics. In this study a subsample (n=2282) of the advance directives cohort study was used. Three different health status groups (good, moderate and poor) were defined based on the EQ-5D and a question on whether they had an illness. For each health status group we calculated the percentage of respondents who indicated the extent to which the items of the Patient Dignity Inventory would influence their dignity as large or very large. Logistic regression analyses were used to investigate the associations between the

perceptions of factors influencing personal dignity and socio-demographics. The percentage of respondents who indicated the factors as having a large/very large influence on dignity at the end of life were not significantly different for the three health status groups, except for three physical items on symptoms, roles and routines. Those items this chapter reports had significantly more influence on dignity for people with a poor health status. Gender, old age, having a partner and having a belief or religion that is important to one's life were associated with the understanding of factors influential to dignity. Health status seems only to affect perceptions of physical factors maintaining dignity at the end of life. This suggests that the understanding of dignity will not substantially change as health status changes and may support starting advance care planning early.

In Chapter 7 the Patient Dignity Inventory was used to investigate and compare the understanding of physicians and volunteers of factors that can influence a patient's perceived dignity, and can make it problematic in practice to preserve their dignity. A written questionnaire including the Patient Dignity Inventory was sent to two groups of caregivers: trained volunteers (n=236) and end-of-life consultants (Support and Consultation on Euthanasia (SCEN)-physicians; n=427). They were asked the extent to which they considered the items as influential on dignity in terminally ill patients, and as problematic in practice in maintaining dignity for patients in the last phase of life. Overall, volunteers more frequently indicated the items of the Patient Dignity Inventory as influential on dignity and problematic in practice to maintain dignity compared with SCEN-physicians. There are some differences in the relative importance of items according to volunteers and SCEN-physicians. It seems that SCEN-physicians consider the physical aspects of suffering as most influential and problematic in practice for preserving dignity while volunteers think psychosocial aspects are most important. This study shows that the role and responsibilities of caregivers involved in the care of terminally ill patients affect the factors that they think influence dignity.

In Chapter 8 the main findings are discussed. Overall, conceptual clarity and the development of well-defined and more standardized descriptions concerning quality of palliative care are needed. In addition, special attention should be paid to the identification of outcomes reflecting the concerns of patients receiving palliative care in these settings, and the development and validation of measurement instruments that can be used for proxy assessment, as many patients receiving palliative care are lacking in capacity and not able to complete self-report questionnaires. Organisations for the promotion and development of palliative care such as the European Association for Palliative Care or the International Association for Hospice & Palliative Care should stimulate and support further development and identification of standardized concepts, definitions and outcomes for palliative care research. These organisations can also help to implement more standardized concepts and outcomes to make research more comparable in order to benefit all researchers in the field.

Research is very important to evaluate present palliative care services and to further develop adequate palliative care. Future palliative care research should not focus solely on cancer patients but also on palliative care for non-cancer patients and those residing in long-term care facilities. In addition to quality of life, personal dignity can be considered as an important outcome measure in palliative care.